



STATE OF TENNESSEE

PROCLAMATION

BY THE GOVERNOR

WHEREAS, Pitt-Hopkins Syndrome is a rare and potentially severe neurological disorder caused by a spontaneous mutation or deletion on the 18th chromosome; and

WHEREAS, Pitt-Hopkins Syndrome is characterized by developmental delays, moderate to severe intellectual disability, breathing problems, epilepsy or recurrent seizures, gastrointestinal issues and distinctive facial features; and

WHEREAS, approximately 500 people worldwide have been diagnosed with Pitt-Hopkins Syndrome, there are likely many other cases that remain undiagnosed since the discovery of the gene in 2007; and

WHEREAS, given its rarity, online support groups play a pivotal role in connecting individuals, families and their loved ones and increasing awareness; and

WHEREAS, the Pitt-Hopkins Research Foundation annually celebrates September 18th as International Pitt-Hopkins Syndrome Awareness Day to raise awareness and funding for Pitt-Hopkins research and this date was chosen to bring attention to the fact that it is a disorder caused by a spontaneous mutation or deletion on the 18th chromosome; and

WHEREAS, the Pitt-Hopkins Research Foundation is a volunteer organization of families and professionals dedicated to finding a cure for Pitt-Hopkins Syndrome through the funding of research, education and advocacy;

NOW, THEREFORE, I, Bill Lee, Governor of the State of Tennessee, do hereby proclaim September 18, 2019 as

Pitt-Hopkins Syndrome Awareness Day

in Tennessee and encourage all citizens to join me in this worthy observance.



IN WITNESS WHEREOF, I have hereunto set my hand and caused the official seal of the State of Tennessee to be affixed at Nashville on this twenty-seventh day of August, 2019.

Bill Lee

Governor

Lee Vengitt

Secretary of State